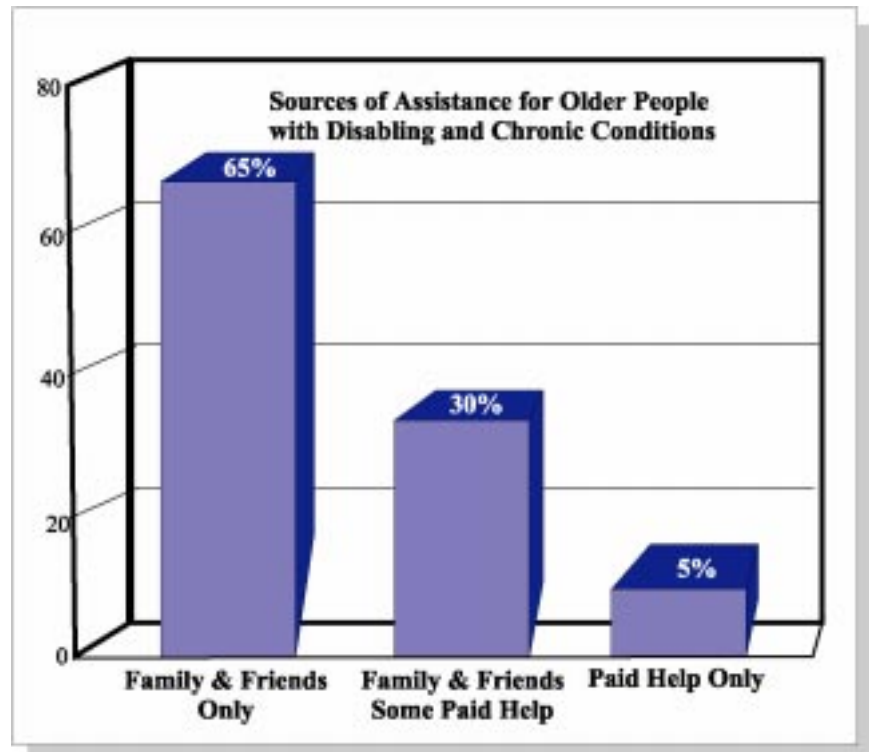




Families, not social service agencies or government programs, are the mainstay underpinning long term care (LTC) for older persons in the United States. According to the most recent National Long Term Care

Survey (1994), more than seven million persons are informal caregivers providing unpaid help to older persons who live in the community and have at least one limitation in their activities of daily living. These caregivers include

spouses, adult children, and other relatives and friends.



1994 National Long Term Care Survey, U.S. Department of Health and Human Services

Of the older persons receiving paid and unpaid assistance, 95% have family and friends involved in their care. Paid home care is the exception, not the rule, for the great majority of older persons with disabilities.

The degree of caregiver involvement has remained fairly constant for more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its older persons. This is despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life. Thus, family



Recognition of Caregivers

The National Family Caregivers Support Program

caregiving has been a blessing in many respects. It has been a budget-saver to governments faced annually with the challenge of covering the health and LTC expenses of persons who are ill and have chronic disabilities. If the work of caregivers had to be replaced by paid home care staff, the estimated cost would be \$45 – 95 billion per year.

National recognition is beginning to be paid to the critical role of families in the provision of LTC. In 1993, President Clinton signed the Family and Medical Leave Act into law to ensure that businesses address the needs of their employees with regard to eldercare. In addition, every November, President Clinton has issued a formal proclamation designating the week of Thanksgiving as National Family Caregivers Week, a period set aside for the nation to honor and support the daily contributions of family caregivers.

In 1999, President Clinton announced the National Family Caregiver Support Program (NFCSP). The NFCSP is one of four LTC initiatives proposed in the FY 2000 President's Budget to help families sustain their efforts to care for an older relative who has serious chronic illness or disability. Under this proposed Older Americans Act program, State Units or Offices on Aging, working in partnership with local Area Agencies on Aging, community service providers, and consumer organizations, will be expected to put in place at least five program components:

- Individualized information on available resources to support caregivers;
- Assistance to families in locating services from a variety of private and voluntary agencies;

Demands on Caregivers

The price paid by caregivers is significant. The National LTC Survey and other research have documented that:

- ***Caregivers dedicate on average 20 hours per week to the provision of care for older persons and even more time when the older person has multiple disabilities;***
- ***Caring for an older person with disabilities can be physically demanding, particularly for older caregivers who make up half of all caregivers. One-third of all caregivers describe their own health as fair to poor;***
- ***Because caregiving is such an emotionally draining experience, caregivers have a high rate of depression when compared to the general population;***
- ***Almost one-third of all caregivers is balancing employment and caregiving responsibilities, and of this group, two-thirds report conflicts in roles that require them to rearrange their work schedules, work fewer than normal hours, and/or take unpaid leaves of absence.***

The National Aging Network

- Caregiver counseling, training, and peer support to help them better cope with the emotional and physical stress of dealing with the disabling effects of a family member's chronic condition;
- Respite care provided in the home, at an adult day care center, or over a weekend in a nursing home or residential setting such as an assisted living facility; and
- Limited supplemental services to fill a service gap that cannot be filled in any other manner.

In 1999, the NFCSP legislation was introduced in Congress and received bipartisan support. The legislation will be further considered in 2000.

Under the authority of the Older Americans Act, the U.S. Administration on Aging (AoA) works closely with the national network of aging organizations to plan, coordinate, and provide home and community-based services to meet the unique needs of older persons and their caregivers. The aging network includes: AoA's Regional offices; 57 State Units on Aging, 655 Area Agencies on Aging (AAA), 225 Tribal and native organizations representing 300 American Indian and Alaska Native Tribal organizations and 2 organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers.

The local AAA is one of the first resources a caregiver should contact when help is needed. Almost every state has one or more AAA, which serve local communities, older residents, and their families. (In a few states, the State Unit or Office on Aging serves as the AAA.) Local AAA's are generally listed in the city or county government sections of the telephone directory under "Aging" or "Social Services."

The Eldercare Locator

AoA supports a nationwide, toll free information and assistance directory called the Eldercare Locator, which can locate the appropriate AAA to help an individual needing assistance for their loved ones, relatives, or friends. Older persons and caregivers can call the Eldercare Locator toll free at 1-800-677-1116, Monday through Friday, 9:00 a.m. to 8:00 p.m., Eastern Time. Eldercare Locator operators are prepared to be of help. When contacting the Locator, callers should have the address, zip code, and county of residence for the person needing assistance.

Working in close partnership with its sister agencies in the Department of Health and Human Services, the Administration on Aging provides leadership, technical assistance, and support to the national aging network of 57 State Units on Aging, 655 Area Agencies on Aging, 225 Tribal and native organizations representing 300 American Indian and Alaska Native Tribal organizations and 2 organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers.

For more information about the Administration on Aging, please contact:

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Eldercare Locator: 1-800-677-1116, Monday – Friday, 9 a.m. to 8 p.m. ET